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## **Title page**

### **Title of review article:**

Palliative care needs of heart failure patients in China: putting people first

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## **Abstract**

### **Purpose of review**

Recognising the rising prevalence of heart failure in China, patients with heart failure have substantial palliative needs. This review highlights recent evidence on the epidemic of heart failure, identifies needs and potential benefit of palliative care in heart failure, and sets future strategic policy and research directions in China.

### **Recent findings**

Epidemiological studies demonstrate the prevalence of heart failure among women is higher than men in China and increases substantially with age. However, few studies have addressed the palliative needs of Chinese heart failure patients. The main themes from this review include: (1) Healthcare providers should be culturally sensitive when assessing symptoms and needs. (2) Locally validated, brief outcome measures are called for to identify symptoms and needs of Chinese heart failure patients. (3) Palliative care should be better integrated into the management of heart failure through increased training for healthcare providers, policy development, financial support, and cultural acceptance of palliative care.

### **Summary**

Large-scale epidemiological studies are urgently needed to assess the current situation of heart failure in China, alongside interventional studies to drive the development of innovative palliative care services to address the needs of Chinese heart failure patients.

### **Keywords**

China, heart failure, palliative needs, symptoms

## **INTRODUCTION**

Cardiovascular disease has become the leading cause of death for Chinese accounting for 44.8% of deaths in rural and 41.9% in urban area, due to a dramatic shift from a traditional to a more 'Western' lifestyle, rapid urbanisation/industrialisation, and aging [1, 2]. Heart failure (HF) is a major healthcare concern with an estimated prevalence of more than 26 million cases worldwide [3\*, 4]. HF in China is recognised as a dominant form of cardiovascular disease, associated with high morbidity and mortality [5\*, 6]. China is now facing a rising epidemic of HF, which has serious socioeconomic consequences [7].

The prevention and care of HF in China should be elevated to a national public policy priority [8]. One way to meet the needs of HF patients and their families is through palliative care. However, palliative care in China still focuses primarily on cancer patients and remains underutilised with those with non-cancer conditions [9\*]. Furthermore, little is known about the palliative needs of Chinese HF patients. It is imperative to review recent evidence on the trend of the epidemic of HF, identify needs and potential benefit of palliative care in HF, and set strategic directions for public health policies and future research in China.

## **EPIDEMIOLOGY OF HEART FAILURE IN CHINA**

The cause of HF in China has shifted significantly from rheumatic valvular disease in the 1980s to coronary heart disease now [10, 11], which is consistent with the results of investigations analysing evolving trends in the epidemiological factors and treatment of hospitalised patients with congestive HF in Shanghai during 1980, 1990, and 2000 based on case records of 2,178 patients (mean age  $64.0 \pm 16.0$  years). They found the rate of HF due

to rheumatic heart disease decreased from 46.8% to 8.9%, and that due to coronary heart disease rose from 31% to 55.7% [12].

A recent review [13] highlighted important epidemiological studies of HF in China. The first and only available national survey of 15,518 adults (aged 35-74 years) from 10 provinces was conducted in 2001 to investigate the prevalence and geographic variation of self-reported congestive HF in China [14]. It showed that the prevalence of HF is 0.9% for the general population (lower than Western countries – 1.2-2.0%), 0.7% for males, and 1.0% for females. Approximately 4 million people in China were estimated to have HF, with a prevalence of 0.4% in people aged 35-44 years rising to 1.0% in those aged 45-54 years, and to 1.3% in those aged more than 55 years. The survey demonstrated that the risk of chronic HF was higher in northern China (1.4%) than in southern China (0.5%), and higher in urban (1.1%) than in rural areas (0.8%). HF is becoming more prevalent in China especially in older people, which imposes a significant socioeconomic burden on individual patients/families, and demands an increasing proportion of healthcare resources to deal with burgeoning rates of hospital admissions/readmissions, disability and mortality, [15\*, 16\*].

As the aged population grows rapidly in China, the prevalence, morbidity, and mortality of HF will continue to increase [17]. Unlike Western countries, the prevalence of HF among women is higher than men in China. The prevalence of congestive HF increases substantially with age, which is consistent with data from other countries [14]. Although the causes of HF vary between cities in China, coronary heart disease, hypertension, rheumatic valvular disease and cardiomyopathy have been recognised as major causes [18]. In addition, reliable data on disease prevalence and incidence of HF in the Asian-Pacific region are lacking [3\*].

Epidemiological data on HF in China is relatively old and is an inappropriate base on which to develop prevention and management strategies.

### **SYMPTOMS AND QUALITY OF LIFE AMONG HEART FAILURE PATIENTS IN CHINA**

Symptom/needs assessment plays a vital role in measuring health status or quality of life in HF [19, 20]. Although the high prevalence and poor prognosis associated with HF has attracted increasing attention [8], new evidence on symptom/needs assessment at an individual level is lacking for Chinese patients. A review from an Asian-Pacific perspective suggests that patients with HF from this region are younger and have more severe signs/symptoms than those in Western countries [3\*]. Recently, a secondary analysis of a cross-sectional observational study was conducted to compare patients' reporting of symptoms in HF between a Western (United States) and an Eastern Asian population (China/Taiwan) [21\*\*]. Interestingly, the results showed that HF patients in China/Taiwan had significantly lower scores than those in the United States across six of eight symptoms analysed: Oedema ( $t = 2.995$ ,  $p = .003$ ), fatigue/increased need to rest ( $t = 3.841$ ,  $p < .001$ ), fatigue/low energy ( $t = 5.881$ ,  $p < .001$ ), shortness of breath ( $t = 6.403$ ,  $p < .001$ ), anxiety ( $t = 2.425$ ,  $p = .016$ ), and feeling depressed ( $t = 2.723$ ,  $p = .007$ ).

This study [21\*\*] highlighted that it is unlikely the Eastern Asian population actually had a lower symptom burden as the two comparative groups had similar characteristics. One possibility could be a cultural difference between Western and Asian patients in reporting symptoms. This is consistent with previous studies documenting that people of an Asian ethnic background often exhibited lower levels of self-disclosure, emotional distress and symptom severity, and were more prone to mask their feelings [17, 22, 23]. Another

qualitative study among cancer patients also reported that Asian patients tended to minimise and normalise their symptoms to avoid worrying or burdening their families [24]. These findings emphasise that symptom reporting reflects the context of the individual's cultural and personal situation [25, 26], and therefore, healthcare providers should be culturally sensitive when clinically assessing patients [27].

Two questionnaires are commonly used when assessing the quality of life of those with HF in China: the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and Chinese Quality of Life instrument (ChQoL) [8]. The MLHFQ contains 21 items and is a psychometrically validated measure assessing health-related quality of life in HF patients [28, 29]. The Chinese version of the MLHFQ has been developed and shown to be satisfactory and comparable to the English version [30, 31]. It was used in the cross-cultural study described above [21\*\*] and also in a small single-centre study of 66 Chinese patients with chronic HF, demonstrating a significant correlation between disease severity and quality of life; the more severe the disease, the higher the questionnaire score [32]. These results are consistent with those from a previous study conducted in the United States showing the questionnaire to be generally sensitive to symptom severity [33].

ChQoL was initially developed based on the concept of health in Traditional Chinese Medicine and proved to be a well validated generic, self-reported health status instrument [34]. It has been used with Chinese HF patients [35, 36]. A small study of 39 in-patients with congestive HF who had undergone treatment with integrative Chinese medicine found that all domains of the ChQoL showed significant improvement after treatment, and the ChQoL was demonstrated to be more responsive to measuring changes in quality of life than two

generic questionnaires - World Health Organisation Quality of Life assessment short form (WHOQOL-BREF) and the Short Form 36-item Health Survey (SF-36), but less responsive than the disease-specific questionnaire - MLHFQ [36]. Although these results suggest that the ChQoL could be considered suitable as an outcome measure for Chinese patients with congestive HF, it may be impractical given the complexity of the questionnaire: 50 items across physical/spiritual/emotional domains which require 10 - 20 minutes to complete. Locally validated and brief outcome measurement tools are urgently needed to identify HF patients' needs and evaluate services in China.

#### **WHAT CAN PALLIATIVE CARE OFFER FOR HEART FAILURE PATIENTS IN CHINA?**

Palliative care has been increasingly recognised as playing an important role along the cancer disease trajectory [37-39]. It is believed that a palliative care approach is also important in patients with HF, even upstream from the end of life phase [40, 41]. Palliative care helps to meet the multidimensional needs of patients and their families. For example, in a cluster randomised trial involving 434 patients in Norway, a palliative care intervention based on consultations with palliative care providers resulted in an increased likelihood of dying at home [42].

Experts and the public increasingly call for the expansion of palliative care to accommodate patients with HF in the provision of patient access to continuous, coordinated, and high quality palliative care given simultaneously with specialist cardiology care [41]. Many professional and policy organisations such as the American Heart Association (AHA) and American College of Cardiology Foundation (ACCF) have published guidelines recommending the integration of palliative care in the treatment of patients with advanced



HF [43], emphasising the potential benefits of supportive and palliative care in the alleviation of symptoms and improved quality of life [44]. However, to date the incorporation of palliative care into the management of HF has been inconsistent for several reasons: the uncertainty intrinsic to the HF disease trajectory with an overlay of comorbidity and frailty, complexities of communication between healthcare providers and patients manifest in silos of care, the use of life saving devices with complex trade-offs, a lack of knowledge about palliative/hospice care, and a limited evidence base [41, 45].

In general, palliative care provision in China is patchy and coverage is poor. According to the 2015 Quality of Death Index, China ranked 71 out of 80 countries, and was reported to be *“facing difficulties from slow adoption of palliative care and a rapidly aging population”* [46]. Four main barriers have been recognised as limiting the development of palliative care in China: a traditional view towards palliative care, financial costs, the absence of national strategies and guidelines, and a severe shortage of professional palliative care staff [9\*, 47\*]. Palliative care in China still remains underutilised for patients with non-cancer diagnoses [9\*]. Although the Chinese government has tried to tackle these issues through policy development, financial support and educational initiatives, the development and spread of effective models of palliative care to meet the needs of Chinese patients has a long way to go.

People with advanced HF often suffer complex multiple symptoms and psychosocial distress because of the nature of their illness and mortality risk [48, 49]. There are numerous international studies describing the experiences/needs of patients living and dying with HF [50-52]. Their families may provide day-to-day care, but are also subject to their own

anxieties, concerns, and potential losses. Palliative care should consider the patient/family dyad as a single unit of care, and support family/informal carers/friends throughout the disease trajectory and into bereavement. However, palliative care is often perceived as limited to comfort care at the end of life, and due to this misconception, it is not requested by the patient/family earlier in the disease course [53]. The provision of effective palliative care to those affected by HF in China demands a multidisciplinary approach in addressing psychosocial and spiritual concerns in a culturally sensitive manner, supporting medication management and financial concerns, and ensuring that the treatment plan is aligned with the goals of care of both patients and families [54].

## **FUTURE DIRECTIONS**

The access and provision of palliative care in China varies significantly across health conditions, geographical locations, and service providers [9\*, 47\*]. In order to improve palliative care provision for HF patients, several objectives should be met:

Firstly, there are few data documenting the epidemiology of HF, or patients' needs in China. Large-scale epidemiological studies are needed to provide a reliable evidence base to inform better HF management, and intervention studies are required to investigate the effectiveness of innovative palliative interventions including Chinese herbal medicine [55]. It is important to conduct high quality clinical studies to assess symptoms/needs and to capture problems/concerns through valid patient-centred outcome measures such as the Integrated Palliative care Outcome Scale (IPOS) [56\*]. The IPOS translation and validation will be launched in 2018 through collaborations with the Beijing Cancer Hospital. A disease-specific measure – IPOS HF in Chinese may be the next logical step.

Secondly, professional and policy organisations must emphasise and incentivise palliative care provision, including end of life care. Although the Chinese Society of Cardiology, part of the Chinese Medical Association, in recently updating the 2002 chronic HF guidelines did not explicitly mention palliative care, it did highlight the importance of prevention and encouraged a broader range of treatment options to improve patient outcomes [57].

Third, putting people before the disease is key to ensuring patient-centred palliative care. Palliative care is about meeting multidimensional needs including information needs [58\*\*-60]. Patients' beliefs and norms within a culture can affect their perception of symptoms, their response, and what they report to healthcare providers [21\*\*]. Therefore, clinicians should be aware of the cultural symbolism and the meaning attached to symptoms when assessing patients [61\*\*]. Responsiveness of the health care system is crucial such as working across services, providing good information, and responding flexibly to the individual's needs [62, 63].

Finally, effective integration of palliative care into the management of HF requires enhanced training of healthcare providers, particularly on the nature of palliative care, elucidating patients' values, goals / preferences, and advance care planning within the ethos of shared decision making. In addition, cultural acceptance of palliative care is critical. If death is consistently viewed as failure rather than an important chapter of natural life, this will continue to impact the adoption of palliative care in China [9\*]. Educational programmes for patients/families, healthcare providers, and the wider public could set the scene for attitudinal change.

## **CONCLUSION**

HF presents a great public health challenge to China due to its changing economic circumstances and aging population. Palliative care has clear applications to HF through its focus on complex symptom management, communication, shared decision making, and advance care planning. Importantly, it provides a support system to help families cope during illness and bereavement. However in China, palliative care still remains a neglected area. Considerable effort is needed to bolster the evidence base for palliative care interventions in HF, to develop outcome measurement and communication training, and ultimately, to change the culture and traditional views towards palliative care in China.

## **KEY POINTS**

- There is an urgent need to conduct large-scale epidemiological studies to assess the current situation and overall trends of heart failure in China, which will provide a scientific foundation for more effective prevention and management strategies.
- Patients' reporting of symptoms relies on the context of the individual's cultural and personal situation, therefore, healthcare providers should be culturally sensitive to assess patients' symptoms and meet their needs.
- Locally validated and practical outcome measurement tools such as the Integrated Palliative care Outcome Scale (IPOS) are urgently needed to identify Chinese patients' symptoms and needs, and to evaluate palliative care services.
- Better integration of palliative care into the management of heart failure requires increased training for healthcare providers, policy development, financial support, and cultural acceptance of palliative care in China.

- As the burden of heart failure in China is substantial and is becoming an important public health issue, high quality studies are urgently needed to investigate the effectiveness of novel palliative care interventions to address the needs of Chinese heart failure patients and their families.

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**Conflicts of interest**

There are no conflicts of interest.

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